

Section 2: Special Questions and Considerations for Ryan White CARE Act Grantees

This section contains two questions that pertain to HRSA HIV/AIDS care planning groups. You should answer these questions in addition to the core epidemiologic questions in Section 1.

Question

1

What are the patterns of service utilization of HIV-infected persons in your area?

In this section of your profile, describe the patterns of service utilization of the HIV-infected persons in your area (see Tables 3-20, 3-21, and 3-22 and Figures 3-12 and 3-13).

Many types of data are available to help you answer this question. Some, such as the CARE Act Data report (CADR), are available everywhere; others are available only in some areas. Recommended analyses using CADR data are described here. Other potential data sources, along with suggested analyses, are described after the illustrative tables and figures for CADR data analyses.

Recommended analyses

- HIV primary medical care, by sex, race/ethnicity, age group, exposure categories, TB status, and viral hepatitis (B and C) status
- Support services, by sex, race/ethnicity, and age group

Notes:

- HIV primary medical care includes the following:
 - medical evaluation and clinical care consistent with US Public Health Service guidelines, including the monitoring of CD4 cell counts; viral load testing; antiretroviral therapy; prophylaxis and treatment of opportunistic infections, malignancies, and other related conditions
 - oral health care
 - outpatient mental health care
 - outpatient substance abuse treatment
 - nutritional services
 - specialty medical care referrals
- Duplicates in CADR data are removed at the provider level. Furthermore, because all the data elements are required elements of the CADR, an agency with a client-level system will be able to compute these analyses for its clients. If a grantee does

not have a way to remove the duplicates from the provider records, these data will be duplicated at the EMA or state level. Use caution when working with these data.

Table 3-20
Comparison of characteristics of CARE Act clients and those of persons with AIDS reported to the CDC HIV/AIDS surveillance system, State X, 2000

Characteristic	CARE Act clients, ^a % (N = 950)	Persons with AIDS reported to CDC HIV/AIDS surveillance system, % (N = 3,500)
Race/ethnicity		
White (not Hispanic)	43	58
Black (not Hispanic)	25	17
Hispanic	29	22
Asian/Pacific Islander	2	2
American Indian/Alaska Native	1	1
Sex		
Male	79	87
Female	21	13
Age (yrs)		
<13	4	2
13–19	1	1
20–44	71	77
≥ 45	24	20

^a Includes all persons who had at least 1 visit for an eligible service during the reporting period. Client counts are duplicated at the grantee level (state or eligible metropolitan area).

Interpretation: This table shows that the Ryan White CARE Act is serving a greater proportion of persons from communities of color compared with the proportion of persons with AIDS in State X. In addition, although most of the clients being served by the Ryan White CARE Act are male, the proportion of females being served is greater than the proportion of females with AIDS. The CARE Act is serving a greater proportion of persons less than 13 years of age and more than 45 years of age compared with the proportion of persons with AIDS in these age groups.

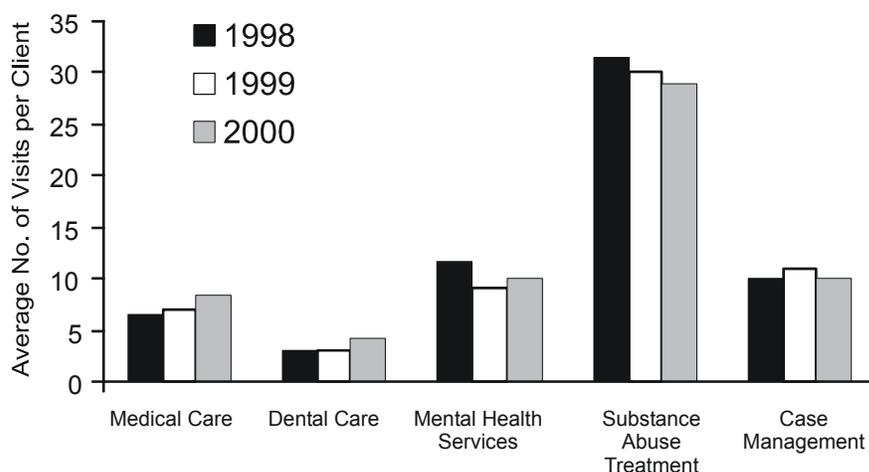
Table 3-21
Visits for services per CARE Act client, by type of Title I service, 2000

	Medical care	Dental care	Mental health services	Substance abuse treatment	Case management
No. of providers supplying valid data ^a	387	167	393	259	568
Average no. of visits per client	8.7	3.8	9.9	29.4	9.8
Median no. of visits per client	5.4	2.7	6.9	9.6	5.6
Range of visits per client	1.0–365.0	1.0–1.9	1.0–128.4	1.0–384.1	1.0–317.0

^a Data based on valid reports only. Valid data defined as providers' reports of complete data both for the number of clients served and the number of visits. Because providers may offer multiple services, a provider may be included in more than 1 service category.

Interpretation: For the 387 medical care providers who supplied data on valid numbers of clients and visits, the average number of visits per client in 2000 was 8.7 (median, 5.4; range, 1.0 to 365.0). The average number of visits for dental care was 3.8 (median, 2.7). For the 167 providers of dental care who supplied valid data, the number of visits per client ranged from 1.0 to 71.9. In 2000, the average number of visits for mental health counseling and treatment was 9.9 (median, 6.9; range, 1.0 to 128.4). Among clients receiving substance abuse counseling and treatment, the average number of visits was 29.4. This figure must be interpreted with caution: visits for substance abuse services include outpatient and residential care. In a residential treatment setting, visits are often counted in terms of inpatient days. The median number of visits for substance abuse treatment was 9.6 (average, 9.8; range, 1.0 to 384.1). Visits with case-management providers averaged 9.8 (median, 5.6; range, 1.0 to 317.0).

Figure 3-12
Average number of visits per client, by type of Title I service, 1998–2000



Note. Data based on valid reports only. Valid data defined as providers' reports of complete data both for the number of clients and the number of visits.

Interpretation: This figure shows a comparison of the average number of visits per client by type of service from 1998 through 2000. The average number of visits per client remained relatively constant for all service categories for the 3-year period, although the average number of visits per client for substance

abuse treatment declined slightly and the average visits per client for medical care and dental care increased slightly.

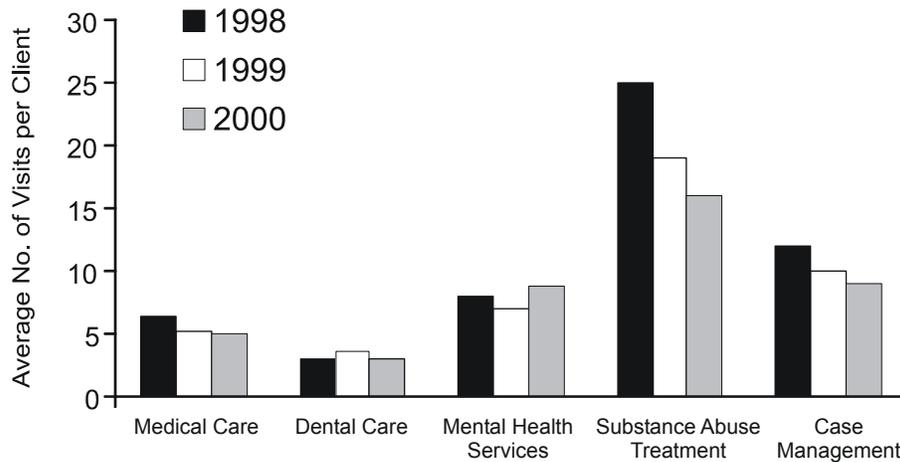
Table 3-22
Average number of visits per client, by type of Title II service, 2000

	Medical care	Dental care	Mental health services	Substance abuse treatment	Case management
No. of providers supplying valid data	414	312	411	183	734
Average no. of visits per client	5.3	2.5	8.6	16.2	8.6
Median no. of visits per client	4.1	2.0	4.8	4.4	5.9
Range of visits per client	1.0–101.6	1.0–16.7	1.0–455.2	1.0–240.0	1.0–194.0

Note. Data based on valid reports only. Valid data defined as providers' reports of complete data both for the number of clients and the number of visits. The actual number of providers is higher than shown for each type of service. Because providers may offer multiple services, a provider may be included in more than one service category.

Interpretation: In 2000, the average number of visits per client to the 414 medical care providers who supplied valid numbers of clients and visits was 5.3 (median, 4.1). The average number of visits for dental care was 2.5 (median, 2.0); among the 312 providers of dental care who supplied valid data, the number of visits per client ranged from 1.0 to 16.7. The average number of visits for mental health counseling and treatment services was 8.6 (median, 4.8; range, 1.0 to 455.2). The average number of visits per client for substance abuse counseling and treatment was 16.2. This number must be interpreted with caution: visits for substance abuse services include outpatient and residential care. In a residential treatment setting, visits are often counted in terms of inpatient days. The median number of visits for substance abuse treatment was 4.4, and the number of visits per client ranged from 1.0 to 240.0. Visits with case-management providers averaged 8.6 (median, 5.9; range, 1.0 to 194.0).

Figure 3-13
Average number of visits per client, by type of Title II service, 1998–2000



Note. Data based on valid reports only. Valid data defined as providers' reports of complete data both for the number of clients and the number of visits.

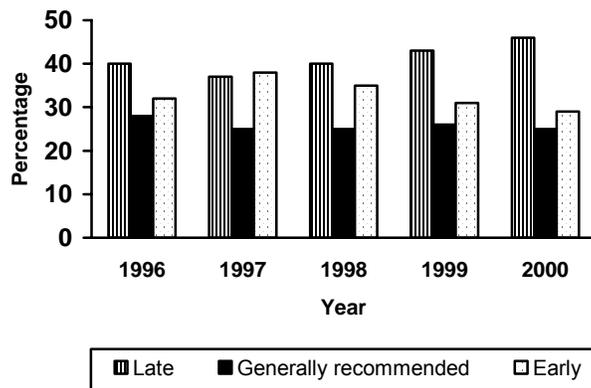
Interpretation: This figure shows that the average number of visits per client consistently decreased from 1998 through 2000 for all services except dental care and mental health. Medical care and case-management services experienced a modest decline in average number of visits per client from 1998 through 2000. The largest decline was in substance abuse counseling and treatment services: the average number of visits per client was 25.2 in 1998 and 16.2 in 2000.

Other recommended analyses and possible data sources

- Demographics of HIV-infected clients receiving services from agencies not funded by the Ryan White CARE Act, including substance abuse, mental health, outreach, and homeless programs as well as community health centers, county clinics, and jails. Examine sex, race/ethnicity, age group, TB status, and exposure categories of these populations. These data may be available at the local level.
- Data from Medicaid and State Children's Health Insurance Program. Examine primary care services and antiretroviral treatment among HIV-infected persons enrolled by sex, age group, and race/ethnicity.
- AIDS Drug Assistance Program. These data may be influenced by Medicaid and other insurance coverage but may provide information on the extent of coverage by this program. Suggested analyses include enrolled persons by sex, age, and race/ethnicity.
- Statewide hospital discharge data. Analyze HIV-related hospital discharges (with any diagnosis of HIV) by year, age group, sex, and, if reliable, by race/ethnicity. Multiply by length of stay to similarly analyze days of hospitalization. Hospital days are a better measure of burden on the health care system than are discharges.
- Survey of HIV Disease and Care and Adult/Adolescent Spectrum of Disease (see Figure 3-14). These studies focus on HIV-positive persons enrolled in primary health care. Analyses include description of the following variables: antiretroviral treatments,

AIDS opportunistic infections—morbidity, mortality, prophylaxis, monitoring of CD4 counts and viral load, immunization coverage, TB screening, and hospitalization. Suggested analyses include examining these variables by sex, age, and race/ethnicity.

Figure 3-14
Proportion of patients who received antiretroviral treatment late, at the recommended time, or early, Adult Spectrum of Disease Study—State X, 1996–2000



Note. Late (CD4 count of <200 cells/ μ L or AIDS-defining opportunistic infection), generally recommended time (CD4 count of \geq 200, but <350 cells/ μ L), or early (CD4 count of \geq 350 cells/ μ L).

Interpretation: This figure illustrates the timing of the initiation of antiretroviral treatment and the proportions of patients whose treatments began at each of 3 times (each time corresponds to a category of CD4 cell count). Of patients receiving care, the proportion whose antiretroviral treatment was begun late increased from 37% in 1997 to 46% in 2000.

Note: The Survey of HIV Disease and Care provides data on inpatient, outpatient, and emergency room visits specific to HIV as well as other variables for standard of care. Using these data, you can compare standards of care among Ryan White CARE Act–supported providers vs. providers not supported by the CARE Act, urban providers vs. non-urban providers, and other variables.

- Supplement to HIV/AIDS Surveillance. For areas collecting population-based data, this study can describe all HIV-infected persons, including those who may not be in care. You should conduct analyses to identify the proportion of persons receiving care in your service area. For persons who are in care, your analysis may include a description of antiretroviral treatments, prophylaxis for opportunistic infections, CD4 and viral load testing, and data on hospitalizations. Analyses of home health care,

mental health services, case management, and service needs may be useful. The analyses of data on persons enrolled in care can also be performed by areas with facility-based data collection. Suggested analyses include examination of these variables by sex, age, and race/ethnicity.

- Client-level data reporting systems. In areas with client-level data systems, such as HRSA's CAREWare, unique client identifiers permit the removal of duplicated counts of service utilization. Track and analyze data carefully to protect client confidentiality and avoid duplicate counts. Select data from providers of outpatient medical care, substance abuse treatment, mental health treatment, and case management. For data from these providers, examine the patterns of HIV service utilization by sex, race/ethnicity, and age group.

Client data allow specialized analyses, including the following:

- Comparison of number and percentage of persons whose first HIV diagnosis was also an AIDS diagnosis and persons whose diagnosis was made in earlier stages of HIV infection (before progression to AIDS). This comparison shows which population groups do not have access to, or are not using, counseling and testing services early in the course of infection.
- Comparisons of persons with AIDS (and HIV where data are available) in a service area and persons receiving services through CARE Act providers may reveal which population groups are underserved. Shortfalls in services for particular populations are likely to differ by type of service.

Question

2

What are the number and characteristics of persons who know they are HIV-positive but who are not receiving HIV primary medical care?

HRSA's HIV/AIDS Bureau (www.hab.hrsa.gov) is working to develop methods to help grantees assess the number of persons who know they are HIV-positive but who are not receiving HIV primary medical care. A recommended framework is described here.

Establishing and using a framework for measuring unmet need for HIV primary medical care

Operational definitions

The following definitions can be strengthened or expanded by a jurisdiction to include, for example, additional HIV-related services. However, the basic definitions meet minimum HRSA requirements for operational definitions.

Unmet need for HIV primary medical care⁶: No evidence of any of the following 3 components of HIV primary medical care: viral load testing, CD4 count, or provision of antiretroviral therapy during a 12-month period.

Met need for HIV primary medical care: Demonstration of one or more of the 3 components during the specified 12-month period.

Inputs

The framework uses 2 types of inputs—population size and care patterns. To measure unmet need for HIV primary medical care according to the basic operational definition, you must first determine the population size inputs and the care pattern inputs for a particular geographic area. The geographic area could be a state, an EMA, or another geographic area, such as a county, region, or public health service area.

- **Population size:** The measure of how many people with HIV disease are living in the area during a particular period. These data come mainly from AIDS and HIV case surveillance.

⁶HIV primary medical care is defined as medical evaluation and clinical care that is consistent with US Public Health Service guidelines for the treatment of HIV/AIDS. For a more detailed definition, see page 87.

Data needed are:

- a. number of people living with AIDS (PLWA) (i.e., aware of status)
- b. number of people living with HIV, without AIDS (PLWH) (i.e., aware of status)

Note: Combining a and b results in the total number of persons who know they are HIV infected.

- **Care patterns:** Measures of how many HIV-infected persons who are aware of their status are receiving primary HIV medical care from any provider (not just Ryan White CARE Act care providers). These data may come from several possible sources: CD4 and viral load reporting in surveillance, studies (e.g., Adult Spectrum of Disease), claims databases (e.g., Medicaid and AIDS Drug Assistance Program), or other sources. Total-count methods provide data in numbers; methods based on sampling typically provide data as percentages.

Data needed are:

- c. percentage or number of PLWA that meet primary care definition
- d. percentage or number of PLWH that meet primary care definition

Unmet need = $(a - c) + (b - d)$.

$(a - c)$ = unmet need among PLWA

$(b - d)$ = unmet need among PLWH

Method 1

A simple framework using data on counts of population and care patterns:

a = number of persons living with AIDS (PLWA)

b = number of persons living with HIV (PLWH)

c = number of PLWA who received specified services in 12-month period

d = number of PLWH who received specified services in 12-month period

Example: Unmet need in State X

In State X, there were 4,291 persons living with AIDS and 3,942 persons living with HIV. The proportion of persons living with AIDS who received primary medical care within the past 12 months was 62%. The proportion of persons living with HIV who received primary medical care within the past 12 months was 27%.

a = 4,200

b = 3,900

c = 3,600

d = 2,000

$$\begin{aligned}\text{Unmet need} &= (a - c) + (b - d) \\ &= (4,200 - 3,600) + (3,900 - 2,000) \\ &= 600 + 1,900 \\ &= 2,500 \text{ persons}\end{aligned}$$

Method 2

A simple framework using counts of population and care patterns based on sampling:

a = number of PLWA

b = number of PLWH

c = % of PLWA who received specified services in 12-month period

d = % of PLWH who received specified services in 12-month period

Unmet need = $[a \times (1 - c)] + [b \times (1 - d)]$

Example: Unmet need in State X

In state X, there were 4,291 persons living with AIDS and 3,942 persons living with HIV. The proportion of persons living with AIDS who received primary medical care within the past 12 months was 62%. The proportion of persons living with HIV who received primary medical care within the past 12 months was 27%.

a = 4,291

b = 3,942

c = 62%, or 0.62

d = 27%, or 0.27

$$\begin{aligned}\text{Unmet need} &= [a \times (1 - c)] + [b \times (1 - d)] \\ &= [4,291 \times (1 - 0.62)] + [3,942 \times (1 - 0.27)] \\ &= [1,631 + 2,878] \\ &= 4,509 \text{ persons}\end{aligned}$$

Summary of Recommended Analyses for Question 2

The analyses summarized here will guide you in analyzing, interpreting, and presenting data describing the patterns of service utilization of HIV-infected persons in your state or EMA. Depending on your local needs, you may choose to perform analyses in addition to those recommended below:

- HIV primary medical care, stratified by sex, race/ethnicity, age group, exposure categories, TB status, and viral hepatitis (B and C)
- Support services, stratified by sex, race/ethnicity, and age group
- Number and characteristics of persons who know they are HIV-positive but who are not receiving HIV primary medical care